



May 18, 2015

The Honorable Fred Upton
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone, Jr.
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Joseph Pitts
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Gene Green
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

CC:

The Honorable Michael Burgess
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Diana DeGette
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Chris Van Hollen
1707 Longworth House Office Building
Washington, DC 20515

Sent via e-mail: Cures@mail.house.gov

Re: Inclusion of H.R. 292 in 21st Century Cures

Dear Congressmen Upton, Pallone, Pitts and Green,

On behalf of the multiple sclerosis (MS) community, the [Multiple Sclerosis \(MS\) Coalition](#) thanks you for your leadership on the 21st Century Cures Act. It is extraordinarily exciting to be part of a concentrated and intentional effort to accelerate the discovery, development and delivery of treatments to people with chronic illnesses and diseases.

The MS Coalition is a group of eight organizations dedicated to providing and supporting critical programs and services for all those affected by MS (patients, their families, and the community at large), as well as funding for research. The primary objectives of the Coalition are to educate, advocate, and collaborate in order to improve, expand, and sustain the efficiency of services.

MS is an unpredictable, often disabling disease of the central nervous system, which interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS.

Neuroscientists are making great strides in many areas of brain research but lack basic information about these populations to help advance their studies. In the past 40 years, there has not been a study to collect and map those people living with MS and their characteristics. We are very pleased that the Committee has included H.R. 292, the Advancing Research for Neurological Diseases Act, in the 21st Century Cures draft legislation (Title I, Subtitle G, Sec. 1122). **We fully endorse the language of this section and urge the continued inclusion of this provision as is in the 21st Century Cures bill.**

This provision would help advance MS research by establishing a data system to collect the size and makeup of the MS population. Currently, no one has an accurate account of how many people in the United States have MS or the demographic characteristics of those living with MS. As a result, MS researchers are working at a distinct disadvantage because they are operating without basic information about the disease. By establishing this data system, it could supply data that points to new environmental triggers, which could lead to a better understanding of the disease and new disease targets.

Again, we thank you for the enormous effort you have invested in drafting this important piece of legislation and for the inclusion of the National Neurological Diseases Surveillance System. We are happy to make ourselves a resource for you as the bill continues through the legislative process. If the MS community can be of any assistance, please contact Lauren Chiarello, Senior Director of Federal Government Relations at the National MS Society at lauren.chiarello@nmss.org or 202-408-1500.

Sincerely,

Douglas G. Franklin
President, Multiple Sclerosis Coalition

Accelerated Cure Project for Multiple Sclerosis
Can Do MS
Consortium of Multiple Sclerosis Centers
International Organization of MS Nurses
Multiple Sclerosis Association of America
Multiple Sclerosis Foundation
National Multiple Sclerosis Society
United Spinal Association